



Department of Health

National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-Outs

Response Form

Question 1: Please tell us which group you belong to? (Required)

Social Research Association – a member organisation for social researchers

Question 2: If you are a member of an organisation or profession, please tell us if you are responding in a personal or private capacity

No, this response is in a professional capacity

Question 3: If the Department of Health or other organisations were to create further opportunities to engage on data security and the consent/opt-out model, would you be interested in attending? If so where would you find it helpful an event to be held?

Yes No

Event location

London

Question 4: The Review proposes ten data security standards relating to Leadership, People, Processes and Technology. Please provide your views about these standards.

Which standard do you wish to comment on?

1 2 3 4 5 6 7 8 9 10

Comments

Question 5: If applicable, how far does your organisation already meet the requirements of the ten standards?

Where 0 = Not at all and 10 = Fully compliant

0 1 2 3 4 5 6 7 8 9 10

Please provide examples which might be shared as best practice

Question 6: By reference to each of the proposed standards, please can you identify any specific or general barriers to implementation of the proposed standards?

Which standard do you wish to comment on?

- 1 2 3 4 5 6 7 8 9 10

Question 7: Please describe any particular challenges that organisations which provide social care or other services might face in implementing the ten standards.

Question 8: Is there an appropriate focus on data security, including at senior levels, within your organisation?

- Yes No

Please provide comments to support your answer and/or suggest areas for improvement

Question 9: What support from the Department of Health, the Health & Social Care Information Centre, or NHS England would you find helpful in implementing the ten standards?

Question 10: Do you agree with the approaches to objective assurance that we have outlined in paragraphs 2.8 and 2.9 of this document?

Yes No

Please comment on your answer

Question 11: Do you have any comments or points of clarification about any of the eight elements of the model described above?

Which standard do you wish to comment on?

1 2 3 4 5 6 7 8

Please provide details

4. You have the right to opt out

There is, in our view, a strong argument that if personal confidential data is only used to help provide local services and run the NHS and social care system or to support research that will improve treatment and care, and if these uses are carefully policed, that there should not be a right to opt-out. The more comprehensive the coverage of this data, the better the research that can be done, and thus the greater the benefits to the health and social care services and their users. Of course, any research that involves primary data collection would allow individuals to opt out from taking part in that data collection exercise.

If, however, there is to be a right to opt-out, then the SRA agrees that there should be more clarity around what this opt-out means for both individuals and researchers.

However, it is not clear how the opt-out will be presented to people. Will everyone be specifically presented with an option when they come into contact with health or social care services, or will people need to specifically choose to opt-out (perhaps in response to a mailout informing everyone about the issue)?

From a research point of view, we would recommend that the opt out is not explicitly offered to everyone as this would, in our view, push up the numbers who opt out to the extent that it would make it difficult to conduct any robust research into either service provision or treatment and care (as the survey coverage would potentially be too low to be able to generalise from it, and those

who do not opt out are likely to be different to those who do potentially introducing serious bias to any results). This will be because many of those who opt-out if explicitly asked are likely to do so as a default option rather than from consideration of the issues.

From a logistical point of view, it is also unclear how and when this would be done.

6. Explicit consent will continue to be possible

There is reference to the fact that if someone has opted out from research they can give their explicit consent for their information to be shared for a specific research study. It is unclear how this would be done – who would approach them to ask if they wanted to take part in a specific study, and, for many studies, how would this differ from the standard recruitment approach? Would this cover the situation where someone gives consent for data linkage of survey data to health data even though they have opted out?

7. The opt out will not apply to anonymised information

We are pleased that the opt out will not apply to anonymised information.

Question 12: Do you support the recommendation that the Government should introduce stronger sanctions, including criminal penalties in the case of deliberate re-identification, to protect an individual's anonymised data?

Yes, we would support this. Would this just cover health data or would it be extended to other data (for example from other surveys or administrative data)? We would support a wider coverage.

Question 13: If you are working within health or social care, what support might your organisation require to implement this model, if applicable?

Question 14: If you are a patient or service user, where would you look for advice before making a choice?

Question 15: What are your views about what needs to be done to move from the current opt-out system to a new consent/opt-out model?

Yes No

Please comment on your answer

Question 16: Do you think any of the proposals set out in this consultation document could have equality impacts for affected persons who share a protected characteristic, as described above?

If people with specific characteristics tend to opt-out at higher levels than others, it is possible that research conducted will under-represent these people which could lead to a lack of understanding of the issues that these people face (for example, in terms of service provision).

The levels of opt-out for specific groups should be monitored to assess whether this is likely to be a problem.

Question 17: Do you have any views on the proposals in relation to the Secretary of State for Health's duty in relation to reducing health inequalities? If so, please tell us about them.

Send your responses to:

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